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Note:

Organ Procurement Organizations may provide resources for discussing death and organ donation with family members.

Introduction

With the recent expansion of the Creutzfeldt-Jakob Disease (CJD) Program in hemophilia treatment centers (HTCs) across the country, much concern has arisen about CJD, the possibility of CJD in the blood supply, and the reception of CDC's CJD Program by HTC patients and their families. This is the beginning of a series of newsletters intended to address concerns identified in treatment centers where the CJD Program

is already in place and to anticipate issues which may arise in centers just beginning the CJD Program. Should you or your patients have any questions, problems, or concerns about the program, please forward them to your Regional Coordinator who will then forward concerns to CDC so that we may address these issues on a national level.

Initiating the CJD Program in Your HTC

Answers to most questions regarding the CJD Program can be found within the CJD Program Procedures Manual contained in the Hematologic Diseases Surveillance Manual notebook. The CJD contact should be familiar with this manual. Contact numbers are provided in the manual should you continue to have questions after reading this newsletter.

Procedures for assurance/IRB approval at your institution should be followed. If you are unsure of the procedures for your center contact your

Regional Coordinator. We strongly recommend that you establish a contact in the pathology department associated with your institution before approaching families about the CJD program.

Please forward a copy of the pathology materials in the CJD Program Procedures Manual to your contact to insure that he/she is familiar with the procedures to be performed. Also, please be sure to forward any updates to these procedures to the pathology department when you receive them.

Similar CJD Surveillance Program Associated With CDC

Your pathology department may ask you about a similar CJD surveillance project for which brain specimens are sent to Case Western Reserve University (CWRU) in Cleveland, OH. The National Prion Disease Pathology Surveillance Center has been established at CWRU in collaboration with the American Association of Neuropathologists and CDC's Division of Viral and Rickettsial Diseases. The major objective of this program is to monitor the presence or absence of new variant CJD and other human prion diseases in the United States by collecting brain specimens from persons with confirmed or suspected cases of CJD or other prion diseases.

Most pathology departments may not be aware that two separate CJD surveillance programs exist, so your pathology department may be unsure about which protocol for specimen collection should be used and where the specimens should be sent.

If brain specimens are being taken from a patient with a bleeding disorder, the pathologist should follow the procedures in Appendices B and C of the CJD Program Procedures Manual found in the green Hematologic Diseases Surveillance Manual notebook. Brain specimens from patients who do not have a bleeding disorder will be part of the surveillance program coordinated by the National Prion Disease Pathology Surveillance Center and should be sent to CWRU.

CDC has prepared a letter for pathologists outlining the distinctions between these two surveillance programs. Your Regional Coordinator will distribute a copy of this letter so that you may forward it to the pathology department associated with your center.

Consent for Participation

It is important to realize that laws in most states require that the next-of-kin sign the consent form for organ donation after the death of a patient.

Therefore, regardless of HTC staff members' communication with the patient regarding his/her participation in the program, the final decision rests with the patient's family.